

# Unlocking autism, one family at a time

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Hopkins-involved study enlists pregnant women to help understand baffling disorder

By Michelle Landrum

**T**he life I had anticipated for my younger son changed the day I learned he has an autism spectrum disorder. But his diagnosis also changed the life I envisioned for myself — for the better: I finally had an explanation for his unusual behavior, and a goal to help find crucial answers about autism.

With April as Autism Awareness Month, I offer a personal perspective on my son's diagnosis and an invitation to similar parents to channel their quest for answers into important research.

My son Clark didn't fit my preconception of an autistic child. He was talkative, saucy and exuberant. My husband and I



had nicknamed him "Quirky Clarkie" because of his intense likes and dislikes, fixation on letters and numbers, focused ability to play independently and propensity for tantrums.

At home, he seemed normal, although more temperamental than

his older brother Adam, with whom he often played. But starting when he was 3, his preschool teachers noted vague "red flags" — he flopped on the floor, played by himself, rolled around during circle time, had tantrums over minor matters and defied teachers. If a child jostled him, Clark couldn't tell an accidental bump from a challenge to fight.

Was there something wrong with my son? I watched and worried for a year, losing precious time for early intervention.

When I finally had Clark assessed at Kennedy Krieger Institute in 2008, the therapist broke the news gently. Clark, then 4½, appeared to have a "pervasive development disorder — not otherwise specified," a long way of saying: Your child is somewhere on the autism spectrum, but we don't really know where.

And, moreover, scientists don't really know why.

Autism's causes remain elusive, and additional research is imperative. Recent figures from the U.S. Centers for Disease Control and Prevention show that diagnoses are rising, to about 1 in 110 children, compared with 1 in 125 two years earlier. The CDC calls it an "urgent public health concern."

If we are to find autism's causes, researchers need to ask questions as early as possible, even while babies are in the womb. They need parents' help — en-



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abling them to follow women from the time they find out they are pregnant through their child's early development. Mothers who have an autistic child and are newly pregnant (or who plan to get pregnant) are vitally important for the study I now work with as part of four national sites: here at the Johns Hopkins Bloomberg School of Public Health, Drexel University in Philadelphia, the University of California, Davis, and Kaiser Permanente in Northern California. The study is called EARLI (Early Autism Risk Longitudinal Investigation). Using biological and environmental data, researchers will examine possible links between genes and environment. As the babies grow, their development will be clinically assessed, which can give parents the opportunity to seek early intervention if "red flags" arise.

It's too late for me to have another pregnancy. But for similar parents who already want another baby, being part of this research could have profound importance — for science and for all families affected by autism. In the broad range of the autism spectrum, Clark is probably moderately affected. Some kids with Asperger's syndrome, on the mild side of the spectrum,

may be almost indiscernible from typical kids. Other children with severe autism might not talk, or might hurt themselves.

My son, through private therapy, a classroom aide and a lot of work at home and at Rodgers Forge Elementary School, is making significant progress. Clark is still quirky, from his deep interest in short-wave radios, clocks, circuits, math and science to his precise memory, which he attributes to a "camera" in his head. He is boldly confident yet socially clueless. He has problems with overly sensitive hearing, anxiety and certain textures, all of which can send him into a tantrum. But Clark is also a deeply loving, intelligent and amusing boy.

Clark knows he has autism, which I've explained as being "wired differently," but he is blessed with oblivious self-confidence. Though his disability has altered my idyllic vision of his future, it focuses me on what Clark — and kids like him — need to thrive, and on how I and other parents can contribute to finding answers. Michelle Landrum, a former editor at *The Baltimore Sun*, is an outreach coordinator for the Early Autism Risk Longitudinal Investigation, [www.earlistudy.org](http://www.earlistudy.org). Her e-mail is [milandrum@jhsph.edu](mailto:milandrum@jhsph.edu).